

An integrated model of exercise support for people affected by cancer: consensus through scoping

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Published version

HUMPHREYS, Liam, CRANK, H., DIXEY, J. and GREENFIELD, D.M. (2020). An integrated model of exercise support for people affected by cancer: consensus through scoping. *Disability and Rehabilitation*, 1-10.

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Abstract

Introduction: Exercise support for people with cancer is a national priority. The purpose of this study was to identify the success factors necessary to create a model of exercise support for people affected by cancer in a large city in the north of England.

Method: Two groups of participants were recruited; people affected by cancer (n=26) and professional stakeholders (n=14) contributing to either focus groups or semi-structured interviews. Data were analysed using framework analysis.

Results: Results from this study suggest that the promotion of exercise is not a priority in routine cancer care. Patients identified a lack of support and difficulty attaining information as a barrier to becoming active, emphasising a gulf between the patients' needs and the health professionals' priorities. People affected by cancer and professionals agreed that exercise was beneficial to cancer patients both during and after treatment. For an exercise pathway to be successful, key factors were identified including accessibility; tailored support; social interaction; affordability; competence of exercise delivery staff.

Conclusions: There was consensus on the importance of exercise and critical factors required to develop a sustainable, accessible and effective service.

Evidence to inform the development of an exercise pathway for people affected by cancer is provided.

Keywords: Exercise referral, Exercise, Physical activity, cancer survivorship, barriers

Introduction

It is estimated that 2.5 million people are currently living with or beyond cancer in the UK, and this is predicted to rise to 4 million by 2030 [1]. 50% of people diagnosed with cancer in the UK survive for ten years or more [2]. Furthermore, survival rates are improving and have doubled in the last 40 years in the UK [2]. Whilst this is positive, cancer and its treatment can take a significant toll on the physical and emotional health

of survivors [3]. Common side effects of cancer treatment include fatigue, functional decline, pain, psychological distress and a higher risk of comorbid conditions such as cardiovascular disease and diabetes [4].

The literature supports the value of exercise for people affected by cancer (PABC) before, during and after active treatment [5,6]. Persistent symptoms and side effects of cancer treatment such as fatigue [7] diminished quality of life [8] and reduced mobility [9] have been shown to improve through exercise. People diagnosed with the most common cancers (i.e. breast, prostate, colorectal), can realise improvements in cardio-respiratory fitness and muscular strength both during and post-treatment[10]. There is a growing interest in the area of prehabilitation [11]. Prehabilitation enables people with cancer to prepare for treatment promoting health behaviours including exercise [12]. Recently, Macmillan Cancer Support in collaboration with the Royal College of Anaesthetists released a report setting out principles and guidance for prehabilitation [12]. Evidence is also accumulating which suggests exercise participation can reduce the risk of further disease [13,14].

Despite this, the provision of exercise support is not currently a routine component of clinical service provision across the UK [15]. As such, PABC have reported unmet needs in accessing professional support and tailored opportunities to safely initiate exercise and sustain exercise participation [15]. However, there is evidence to suggest cancer survivors who have received recommendation to exercise from health professionals (e.g. oncologists, surgeons, GPs, and clinical nurse specialists) are more likely to engage [16]. As far back as 2013, the National Cancer Survivorship Initiative (NCSI) [17] advocated cancer care pathways integrate the concept of exercise-related support into personalised care pathways, ideally risk-stratified. The NCSI recommendations were accepted and included in the Cancer

Taskforce recommendations of 2015[18] and subsequently in the NHS England Long-Term Plan[19]. That is, by 2021, “personalised care” will include a holistic needs assessment, care plan and health and wellbeing information and support[19]. Ultimately the intention is to support and empower people to manage their care and maximise the potential of community support[19].

The complexity of designing and implementing exercise services requires creative collaboration and partnership working to achieve effectiveness and sustainability aims[20], [21]. Understanding how exercise services can be implemented to suit the needs of PABC and how clinicians can refer into those services could lead to cancer survivors being better able to self-manage and result in improved health outcomes [22].

Primary Aim

The primary aim of the project was to identify critical factors needed to create a model of exercise support for people affected by cancer.

Secondary Aims

Secondary aims were to capture considered perspectives of PABC and key professional stakeholders on constructing a pragmatic cancer and exercise referral service including operational processes, referral mechanisms, commissioning issues, financial and cost implications, and programme content.

Methods

Study design

We used a qualitative research study design involving focus groups and semi-structured face-to-face or telephone interviews.

Location

This study took place in Sheffield, United Kingdom across a number of institutions and organisations including Weston Park Cancer Centre, part of Sheffield Teaching Hospitals NHS Foundation Trust. Physical activity provision in Sheffield includes Sheffield Hallam University and the National Centre for Sport and Exercise Medicine (NCSEM). The NCSEM Sheffield model has previously been described elsewhere else [23].

Research governance

Ethical approval for the study was obtained from NRES Committee East Midlands - Leicester (**REC Ref: 14/EM/1021**). The study was registered with and received project authorisation from the Clinical Research and Innovation Office, Sheffield Teaching Hospital NHS Foundation Trust.

Participant recruitment

People affected by cancer

For the purposes of this study, PABC covered a range of people affected by cancer who represented various stages along the cancer pathway. We aimed to explore a broad range of experiences. Participant needs and preferences for exercise rehabilitation were included, such as prognosis, stage of treatment, previous exercise experiences, tumour type, functional limitations, gender, ethnicity, and age. Inclusion criteria were

age >16 years, have previously been diagnosed with cancer, and an ability to understand and speak English to a sufficient standard to allow participation in a focus group or interview session. Exclusion criteria were any physical, neurological or mental health impairment or disease that would limit the participant's ability to participate in focus groups or interviews.

Poster advertisements were placed in out-patient department waiting rooms at Weston Park Cancer Centre and also at the local Weston Park Cancer Information and Support Centre. Interested individuals with a cancer diagnosis contacted the study team by telephone or email. A member of the university research team assessed the individual's eligibility for the study according to the inclusion and exclusion criteria. Patient's gender, age, ethnicity and tumour type were recorded. Potential participants were sent a study pack including a participant information sheet and study consent form, a study reply form, and free post envelope. Individuals were contacted by researchers to arrange a time and date to attend a focus group or to arrange an interview in person or by telephone. PABC were re-reimbursed travel expenses to the value of a public transport city-wide travel ticket.

Professional Stakeholders

A comprehensive list of key professional stakeholders was identified through collaboration with the National Centre for Sport and Exercise Medicine Sheffield and Weston Park Cancer Centre. Professionals were those individuals or organisations whom may have a role in contributing towards the delivery of a future cancer and exercise referral service such as health professionals (oncologists, clinical nurse specialists), leisure service providers, local authority, charitable organisations, public and private sector organisations.

Participants

A convenience sample of 26 PABC agreed to take part in the study (male n= 8; female n=18; mean age = 53 years old; time since diagnosis mean = 7 years; 96% White British). Cancer types represented were breast (n=12), leukaemia (n=5), prostate (n=2), non-Hodgkin lymphoma (n=2), multiple myeloma (n=1), melanoma (n=1), adenoid cystic carcinoma (n=1), bowel (n=1), sarcoma (n=1). Participants were at varied stages in the cancer pathway; currently in treatment (n=6); completed treatment with confirmed remission (n=12); secondary/advanced cancer (n=8).

A total of 14 professionals participated representing a variety of professions and organisations from across the city. Clinical roles included consultant oncologist (n=2), consultant in exercise medicine (n=2), GP (n=1), clinical nurse specialist (n=1), physiotherapist (n=1), radiographer (n=1), clinical psychologist (n=1). Non-clinical professional roles included academic health researcher (n=1), exercise referral specialist and community leisure provider (n=3) and public health commissioner (n=1).

Data collection

Two focus groups (n=3 and n=6) for PABC were held at a university facility, close to the cancer hospital. Each focus group lasted up to 90 minutes. In total, the research team conducted 31 interviews; 17 interviews with PABC and 14 professional stakeholder interviews. Interviews with PABC lasted between 13 and 49 minutes (median = 25 minutes). Interviews with professionals lasted between 17 and 69 minutes (median = 34 minutes). All focus groups were conducted with two researchers present and interviews were conducted by one member of the research team. Two members of the team are experienced in qualitative research (one female and one male). An interview schedule, developed by the research team, was used to structure the discussions but allow

flexibility. Table 1 shows the interview schedule topics and sample questions from the PABC and professional stakeholder schedules. All interviews and focus groups sessions were audio recorded. The audio recordings were transcribed verbatim by an independent source and then checked for accuracy by one researcher. After 14 professional interviews, and 17 interviews and two focus groups (n=10) with PABC there was a consensus agreement between the interviewers that no new data were emerging and therefore data saturation had been achieved.

Data Analysis

Framework analysis was used[24]. Framework analysis consists of five inter-connected, but distinct stages for analysis: familiarisation, identifying a thematic framework, indexing and sorting, reviewing data extracts, and data summary and display[24]. The unique aspect of this methodology is the latter stage where associations between themes are made and related to the research objectives. All interviews were coded using the NVivo qualitative data-indexing package (NVivo 10) with a member of the research team identifying the initial thematic structure. Two researchers independently reviewed the thematic framework and consensus was reached on the final themes.

Results

Results are displayed according to key themes and sub-themes that arose, in line with the framework analysis technique[25]. We identified four main themes for PABC and three main themes for professional stakeholders. Specifically, for PABC thoughts on exercise following a cancer diagnosis, barriers to participating in exercise, lack of advice from clinical team, and critical factors for an exercise service were identified as main themes. These themes and their subthemes are described in Table 2. For professional's options on exercise for PABC, barriers to implementing an exercise

referral service for PABC, and critical factors to ensure a service is effective were identified as main themes. Table 3 illustrates these main themes and corresponding subthemes. Quotes are included to illustrate key themes for PABC and professionals.

PABC

Theme 1: Thoughts on exercise following a cancer diagnosis

It was evident, for the most part, that PABC participants recognised the positive impact of exercise.

Health benefits of exercise. PABC had an innate sense that there is a positive impact from exercising.

“I just think any exercise has got to be positive, you know, however small”

(P8, male, 50, prostate cancer)

Identified benefits were; potential weight loss, improved strength, reduced fatigue and improved mental wellbeing.

“I just feel so much better in my head when I do exercise, and I think it copes”

(P2, female, 45, breast cancer)

PABC recognised the merits of exercise in preparing for treatments, such as surgery.

“Well any exercise is going to be positive because the fitter you are going into an operation, it’s got to be beneficial for anybody” (P8, male, 50, prostate cancer)

"I think it is something that is part of the treatment. The exercise can assist the treatment and help you through it." (P1, male, non-Hodgkin's lymphoma, 64)

Loss of personal control following a cancer diagnosis. PABC agreed loss of control following a cancer diagnosis was a commonly experienced phenomenon. Becoming

more physically active was seen as a mechanism to regain control of their body and of their lives more generally.

“So the stronger and fitter I am, the more I feel like I can deal with things, and that actually I'm not ill how can I be ill if I can train and do this and run and cycle to wherever and back?” (P4, male, 41, adenoid cystic carcinoma)

PABC identified common experience of a sense of passivity during treatment, of things being done to them. Conversely, exercise was recognised as something which enables self-sufficiency and retains or restores independence.

“I think there's such good evidence that physical exercise reduces your risk of your cancer coming back, you know, there's a mass of literature out there that shows that and you're so out of control that I think if you are given that information at the right point then that gives you a bit of control back” (P22, female, 56, breast cancer)

“I think it does help with self-esteem and does help with a sense of control” (P21, female, 52, breast cancer)

Enhancing recovery from cancer. PABC recognised the merits of activity promoting their recovery.

“You know, you end up I think recovering quicker even if it's literally a walk to the end of the garden path and back.” (P14, female, 49, non-Hodgkin's lymphoma)

PABC reported the benefits of regaining fitness on speeding up recovery. Experiences of being active impacted on their fitness for treatment and promoted recovery.

“It's better to rehabilitate, help people from a rehabilitation point of view and put them in a situation where they're strong enough to go back to work and be productive again, rather than just abandoning them and allowing them to become a couch potato, which is going to be even more of a drain on the NHS ultimately.” (P9, male, 48, sarcoma)

Theme 2: Barriers to participating in exercise

Despite acknowledgement that exercise was positive for their health, PABC identified many barriers to exercising.

Fear of making their health worse. Fear was identified as a major barrier to exercise.

PABC were afraid of making their condition worse, and were uncertain of their exercise capacity and limitations.

“You need to know that you're not going to hurt yourself, you're not going to be risking, you know.” (P14, female, 49, non-Hodgkin's lymphoma)

“I think its fear of doing some damage.” (P13, female, 44, breast cancer)

“I’m scared because my bones are, you know, in a state, and I’m scared of making them worse.” (P23, female, 47, multiple myeloma)

Low confidence in their ability to exercise. PABC acknowledged the impact cancer treatment had on their mood and confidence.

“I mean the main barriers I think are to do with confidence, lack of confidence,” (P9, male, 48, sarcoma)

“You go in where people are fully fit and you’re automatically a failure” (P19, male, 39, leukaemia)

Cancer-related fatigue. Fatigue was identified as a significant barrier preventing PABC from exercising.

“One of the biggest challenges of the whole day is just getting out of bed” (P22, female, 56, breast cancer)

“I feel quite lethargic and very unfit.” (P25, female, 54, breast cancer)

“It’s obviously fatigue isn’t it, and there’s just like I say a lack of energy” (P17, female, 58, leukaemia)

Theme 3: Receiving advice on how and when to exercise

No support from clinical teams. PABC expressed their difficulty in getting specific

exercise advice from their clinical teams.

“I think none of this stuff has been introduced to me by anybody in the health service.” (P22, female, 56, breast cancer)

Others were surprised that they had to search for information rather than it being forthcoming.

“They’re not going to come to you, that’s the thing. If you want it you’ve got to go and look for it and find it.” (P3, male, 71, prostate)

Lack of encouragement from health professionals. Over-protection and a sense of feeling cosseted by health professionals during their treatment was an additional explanation as to why PABC were not encouraged to be active.

“A very, what’s the word I’m looking for, risk averse culture to saying that anything might help when it might not help, because they don’t want to give people more hope” (P4, male, 41, adenoid cystic carcinoma)

“People interpret taking care of you as wrapping you up a bit” (P10, female, 53, melanoma)

“I mean nobody’s going to be encouraging you to. In the current environment, your GP ain’t going to encourage you, then the hospital staff generally don’t encourage you, you know.” (P9, male, 48, sarcoma)

The timing of the discussions about exercise is important. PABC were asked their opinion on the optimal timing of an exercise conversation with their health care professional. Some felt exercise should be discussed at diagnosis to ensure it was considered as an important and integral component of the treatment plan.

“I’d have liked someone to, to give me advice at an early stage so even when I was having chemotherapy surgery, radiotherapy.” (P6, female, 63, breast cancer)

“So the sooner it’s discussed the better, otherwise you don’t have the confidence maybe a year or two in.” (P14, female, 62, breast cancer)

PABC also expressed information saturation around diagnosis and the start of treatment and a limit to their ability to absorb the overwhelming amount of information provided. Thus an exercise discussion was not a priority for discussion at that time.

“I really would have felt that they just had no insight into what my focus was at that time.” (P22, female, 56, breast cancer)

“I think like if someone had tried to embark on talking about physical exercise to me when I was in the middle of all that, I think I would have been a bit like no you’re all right, I just want to eat cake.” (P2, female, 45, breast cancer)

Theme 4: Critical factors for an exercise service

Social/peer support. The majority of PABC agreed the social aspects of any exercise referral service provided benefits.

“I think anything that can get you out and speaking to other people.” (P11, female, 52, breast cancer)

“If there was a walking group, people with similar experiences and they were walking and talking, and supporting each other, then there might be a double benefit there, rather than just than just so, you know, like I say, the physical benefit, there’s a psychological support mechanism there as well” (P4, male, 41, adenoid cystic carcinoma)

Potential benefits of an exercise intervention to increase motivation, adherence, and encourage people to interact and make connections were identified.

“You need outside stimulation, you know, and it, it’s so important as far as your recovery is concerned and I think it is, to me, you know, group-based would be the most effective way without a doubt.” (P9, male, 48, sarcoma)

The financial implications of a cancer diagnosis. PABC acknowledged the impact of financial uncertainty many experience during cancer treatment may impact on their decision to exercise .

“I can understand that, but most people are in financial difficulty if they’re just coming out the other side of, of cancer.” (P16, female, 54, leukaemia)

"A number of cancer patients are going to be out of work or off sick, or facing the possibility, like myself, of not being able to return back to a job, certainly not a high paid job." (P5, female, 42, breast cancer)

On the other hand, PABC also expressed a willingness to make a modest contribution to an exercise intervention. Participants felt paying for a service will increase commitment.

“It can’t be too expensive, but at times the fact that you’re paying a little bit is encouraging you to come.” (P18, female, 62, leukaemia)

“I think you have more commitment to the services you buy from.” (P10, female, 53, melanoma)

“I don’t think the resources would be there to make it completely free. I think a modest contribution would be, would be nice.” (P7, female, 48, breast cancer)

Exercise must be tailored to the individual. PABC expressed the need for a tailored exercise intervention dependent on individual needs and preferences.

“I think people need individual advice about what’s best for them.” (P24, female, 65, breast cancer)

"An assessment before you go to your first session, they identify what your needs are, then it’s completely tailored to your needs, so everybody is doing a different programme." (P26, male, 60, bowel cancer)

A broad and flexible service to cater for differing needs was felt to be important. This would be facilitated through an initial assessment to identify individual needs and goals, followed by a choice of exercise options.

“I think it has to be a menu of options because it affects all shapes, sizes, ages.” (P25, female, 54, breast cancer)

"Have a whole spectrum of things like, a selection box of chocolates, you know!" (P21, female, 52, breast cancer)

PABC need to be taught how to pace their exercise. PABC discussed the need to learn the art of pacing of exercise as an enabling facilitator. PABC were concerned about doing too much and suffering later. A slowly progressed exercise programme was identified as most helpful and avoiding a “boom and bust” approach.

“There may also be a tendency for cancer patients to overdo things, which wouldn’t actually help recovery” (P5, female, 42, breast cancer)

“I’d have welcomed some advice early on. Because I had to learn the hard way. If I did too much I went to bed for a day to recover.” (P20, male, 41, leukaemia)

Exercise professionals need to appropriately trained. Exercise professionals trained in cancer rehabilitation were recognised as an essential part of an exercise referral service.

“So there’s probably not enough expertise out there even in the clubs and groups or whatever, to know what to provide for rehabilitation.” (P25, female, 54, breast cancer)

“I think having the notion of having exercise specialists is a good one” (P10, female, 53, melanoma)

Trained staff instils confidence in PABC with the knowledge they are credible, skilled, knowledgeable and trustworthy professionals.

“They need to have that knowledge or access to the professionals” (P8, male, 50, prostate cancer)

“Somebody appropriately trained, because just going to anybody you could do more damage.” (P15, female, 54, breast cancer)

Professional stakeholders

Theme 1: Opinions on exercise for PABC.

Endorsement of exercise. It was evident during the interviews that professionals had

positive views on exercise for PABC, their rationale for endorsing exercise were founded upon the perceived benefits.

“I think there is increasing evidence that it does have a role in terms of general rehabilitation of patients.” (P28, oncologist, female, clinical)

The professional's endorsement of exercise was described in the following ways: helping a person find some normality, helping a person's recovery from treatment, reducing the likelihood of cancer recurrence and improving mental wellbeing.

“Exercise to me is just such an integral part of getting people back to normality. It changes people's lives, it changes people's outlooks, so I think this programme of actually trying to get people from a cancer background is, is wonderful.” (P31, public health commissioner, female, non-clinical)

“It can physically put them in a better position for reducing recurrence as well.”

“It doesn't have to just make people fitter it can reduce people's levels of depression” (P34, clinical nurse specialist, female, clinical)

The need for tailored exercise. Professionals recognised that no two cancers are the same and therefore it is not feasible for all patients to receive the same service.

“You can't force all patients into one service, for some people a walk to the end of the road would be enough” (P36, physiotherapist, female, clinical)

“One size doesn't fit all.” (P40, exercise medicine consultant, male, clinical)

It was identified that patients will have their own fears, reactions to treatment, attitudes to exercise and fitness levels. Any programme would need to be personalised on each individual's limitations and needs.

“There'd need to be some sort of assessment as to what the actual needs (are) and what that particular patient's going to benefit from.” (P27, oncologist, male)

Communicating the exercise message. The optimal timing to discuss exercise with a patient was a frequently discussed topic. Some professionals felt that the discussion should be as early as possible.

“So I would be saying that needs to happen really early on, so that the patients are aware that exercise is an important part of the health profile. Then gradually as you're working through that's part of the conversation and it's part of the conversation that the clinician has right at the very beginning, rather than something that happens at the end.” (P37, academic health researcher, male, non-clinical)

However, it was acknowledged that some people may not be ready to discuss exercise and the timing of the discussion is dependent on the individual.

“I think it's probably one of the last things on a lot of people's minds, to be thinking about it at such an early stage. I think you've got to play to that person's needs.” (P35, radiographer, female, clinical)

Professionals felt that the message of the importance of exercise should form part of every cancer care pathway and should be as well embedded as discussing traditional cancer treatment options and management plans.

“I believe it should be in the care pathway but again that depends on the individual some will not want to hear about exercise.” (P36, physiotherapist, female, non-clinical)

“It probably shouldn't be seen necessarily as something that just comes at the end of treatment, but integrated through the whole pathway.” (P28, oncologist, female, clinical)

Theme 2: Barriers to implementing an exercise referral service for PABC

The financial implications of exercise options. Professionals acknowledged that people

affected by cancer can face financial difficulties thus there were recognised affordability concerns of exercise sessions if it were to be associated with a charge/cost.

"I can imagine there being groups of patients who would really struggle to afford attending sessions." (P27, oncologist, male, clinical)

Professionals also felt that a service should not be free of charge but a small cost may encourage engagement and patient ownership of a programme.

"I think having a small cost to the patient sometimes can encourage engagement and buy-in, and sometimes just providing stuff for free, there is a risk that it's taken for granted and, and patients may be less likely to attend regularly." (P27, oncologist, male, clinical)

Challenges to promoting exercise to PABC. Professionals were consistently concerned that time and workload pressures are a barrier to giving exercise advice. The primary priority to focus on medical treatment prevents exercise discussion being a top priority during a clinic consultation.

"Time is a factor, time for healthcare professionals who don't feel they've got time to give the advice." (P38, exercise medicine consultant, female, clinical)

"I mean the challenge is obviously time is, is precious" (P28, oncologist, female, clinical)

"I suppose from personal experience of working in secondary care, you know, people are really, really busy" (P31, public health commissioner, female, non-clinical)

Professionals will not refer to exercise services due to a lack of trust. Lack of trust was the most discussed barrier for a professional referring a patient into a service. A referral into a service was identified as an endorsement of that service.

"Referring a patient to a service is me endorsing that service so I have to be sure it is of good quality." (P36, physiotherapist, female, clinical)

“Quality assurance to convince health professionals that, you know, they're referring on to a suitable route into exercise. Because I think, you know, that's where, where it can fall down as well.” (P29, exercise referral specialist and community leisure provider, female, non-clinical)

Health professionals would be reluctant to refer to a service they did not trust to provide safe and effective care.

“I wonder if they're, they're scratching their heads and thinking, well actually, what are, what are those, those exercise referral instructors doing with the people that I send, are they, you know, are they competent?” (P29, exercise referral specialist and community leisure provider, female, non-clinical)

Theme 3: Critical Factors to ensure a service is effective

Professionals interviews identified a number of critical factors required to ensure a referral service was effective.

Exercise options must be easily accessible for PABC. Ease of access was acknowledged as a critical factor for patient engagement, both in terms of the location of the service and whether people can access it easily (i.e. transport). The setting can be a negative factor for individuals, for example, travel time can affect a person's wish and ability to attend.

"Accessible, it's got to be done really in community venues, ideally the catchment of the patient will be in that community rather than travel to the other side of the city, in order to access it." (P30, exercise referral specialist, male, non-clinical)

Ease of accessibility for the referrer was also considered important Involving a simple referral process so the referrer is not burdened with additional and unnecessary administration.

“I think the key steps are, having a simple mechanism for clinicians recommending it to patients and then having identified points to, to refer patients to.” (P27, oncologist, male, clinical)

“The more difficult you make it the more likely people will not engage” (P32, GP, male, clinical)

An exercise service must be effective and sustainable. Professionals discussed the importance of long-term sustainability of any future exercise service. A robust evaluation was highlighted as an essential factor to convince commissioners and to develop a model that can be replicated.

“From a commissioning side, it’s about proving that something has made a difference and that it has made a change.” (P31, public health commissioner, female, non-clinical)

“There’s got to be some understanding of why it works and how it works, so understanding the theoretical position as well as the content of the intervention and, and making sure you’re delivering it appropriately.” (P39, clinical psychologist, female, clinical)

“Need to understand that the intervention can be replicated and rolled out, and can be scaled up, so there needs to be an understanding of what are the active ingredients within that intervention, why is it working and for who, and can you train people in it, can you deliver it as a model to roll out?” (P37, academic health researcher, male, non-clinical)

Exercise professionals need to be appropriately trained. Professionals recognised the importance of exercise professionals who were appropriately trained, competent and experienced.

“The challenge is training and being able to get the right level of training in an accessible place.” (P29, exercise referral specialist and community leisure provider, female, non-clinical)

“Identifying suitable people who would be able to take a lead on supervising what’s going on and, and providing that sort of tailored input for patients.” (P28, oncologist, female, clinical)

“I think it’s about equipping the people that are delivering some of this stuff with the relevant qualifications and, and probably some of that experience as well.”

(P33, exercise referral specialist, female, non-clinical)

Discussion

Despite health professional awareness of the benefits of exercise, people affected by cancer interviewed in this study were not routinely or consistently provided with information, support or encouragement. PABC recognised the potential benefits of physical activity and exercise on regaining control, enhancing recovery and managing side effects such as cancer-related fatigue. Barriers to participating in exercise included low confidence and fear of making things worse. Identified critical success factors were accessibility, sustainability, peer support, and an appropriately trained and credible workforce.

Importance of exercise

Current health policy emphasises the need for health services which focus on the needs of the patients and empower patient choice [26]. Overall, professionals and PABC agreed that exercise was beneficial to patients during and after cancer treatment. Professionals advocate the benefits of exercise which include physical motivators (e.g. weight management, improved fitness and strength, and improved energy), and psychosocial motivators (e.g. peer support/contact, feeling of control, improved confidence). Additionally, PABC identified barriers to being physically active that included physical factors (e.g. fatigue, pain), to psychosocial factors (e.g. lack of confidence, and lack of support, fear). These findings concur with previous research on barriers and motivation for people with cancer [27]–[29]. Thus, when designing an exercise referral service strategy incorporating the key motivators and limiting the barriers into an implementation strategy would be beneficial [30].

Results from this study suggest that promotion of exercise is not yet a priority in routine cancer care. It has been reported that 56% of clinicians did not discuss exercise with their patients [31]. Lack of exercise advice or referral has been discussed in previous research [29]. In our study, the main barriers for health professionals referring into a service appear to be lack of time during consultations, lack of knowledge, and lack of trust of referral pathways they will be referring into. These findings are consistent with previous research [21], [32]. Lack of time is the number one barrier for promoting exercise to cancer patients[33]. Furthermore, patients identified a lack of support and difficulty attaining information as a barrier to becoming physically active. Insufficient professional advice, coupled with a desire for information results in some cancer patients seeking out information about exercise themselves[34]. This information could be from less reliable sources[34]. NICE guidance cites a lack of consistent and appropriately delivered advice on physical activity or exercise in primary and secondary care [35]. A possible reason for this is a lack of formal training on health behaviour issues [36]. Considering the increasing numbers of cancer survivors this will need to alter in the future as interests move from acute care to managing long term health [37]. Especially as cancer clinicians can have a 'gatekeeper' role in motivating people affected by cancer to be more physically active [36].

Although consensus regarding an ideal time to start the conversation about exercise was not reached in our study, previous research has identified the ideal 'teachable moment' is within the year after diagnosis [38]. It is likely to be an iterative conversation at several time points and dependent on individual need and circumstance[39]. Uptake of exercise is an issue, particularly during the active treatment phase[39]. Therefore exercise is not considered until after medical treatment has completed by which time impairments that restrict participation and physical

function have likely developed[39]. Connecting PABC to prehabilitation early in their cancer care shows great promise[40]. Introducing exercise pre-treatment has been shown to reduce functional decline, improve treatment tolerance, and improve exercise adherence[41]. However, there are significant gaps in the prehabilitation research with regard to screening, length of intervention before treatment, and dose of the exercise intervention[41].

Critical factors for an exercise pathway for cancer patients

For an exercise pathway to be successful, there are many critical factors that need to be met. For professionals, the pathway needs to have a simple referral process, and be easily accessible. Time and locality of opportunities have been identified as barriers to using a referral pathway [42]. Time commitment increases substantially if a person relies on public transport [43]. Previous research has demonstrated that the relative proximity of exercise resources is related to exercise participation [44]. Professionals and patients also discussed the issue of the costs of a service. It was agreed that people affected by cancer can face financial difficulties. Cancer patients incur many indirect costs, such as transportation, childcare, and lost wages [45]. Interestingly both groups of participants agreed that any exercise service promotion would need to be affordable but not free of charge to encourage participant motivation.

PABC and professionals are also in agreement that any referral pathway needs to be tailored to an individual's needs and limitations. Bourke and colleagues [46] recommend exercise prescriptions are tailored to ensure safety and effectiveness. Additionally, not all patients will be interested in participating in structured activities such as a gym facility [47]. Thus, it is important that a referral pathway offers a menu of activities so that the patients choose activities that interest them [37]. There is evidence that offering a variety of activities, that are less expensive and give a degree of personal

choice can improve long-term adherence [48]. Providing tailored advice might also alleviate some of the fears that patients have regarding exercise. PABC also identified group activity as a key motivator for being physically active as they felt that group activity will help them interact and socialise. Group based exercise can create a sense of belonging and sociability rather than just exercising [48], [49]. Previous research found that having activities tailored to their ability and group support were two important benefits of a community-based exercise programme[50].

The need for trained exercise staff was a recurring critical factor for success of any referral programme. This finding is supported by previous qualitative research [49]. Qualified exercise professionals are central to a referral pathway [51]. Indeed, NICE guidelines stipulate minimum qualifications for exercise professionals devising exercise programmes. These are a Level 4 qualified exercise professional with a recognised exercise referral qualification and relevant CPR qualification [52]. Level 4 refers to a “Specialist Exercise Instructor” and is the highest level of registration on the Register of Exercise Professionals [53]. Having a recognised kite-mark and quality standard reassures health professionals of the competencies of the staff receiving referrals. Professionals in this study stated that a lack of trust of the service they are referring to would be an obstacle. Previous research found physicians are reluctant to refer patients because of safety concerns[28]. An exercise pathway should aim to build trust with the referrers. Furthermore, health professionals should refer to a pathway that is quality assured as the clinician will attain overall clinical responsibility for the individual [32]. The lack of clarity of who is legally responsible for a patient in the incident of an adverse event might inhibit exercise referral pathway [32]. Improving communication between health professionals and exercise providers will help clinicians

keep track of their patients [54]. Providing health professionals with feedback of their referred patient will also help improve trust in a referral service [54].

Professionals also identified a well-planned evaluation as a critical factor. Exercise referral pathways can often lack regulation, quality assurance, defined goals and robust evaluation [54]. According to NICE [35] policy makers and commissioners should only endorse exercise referral pathways that are properly designed to determine effectiveness.

Limitations of the study

Some limitations need to be taken into consideration when interpreting the results. The sampling strategy may have attracted individuals who already have positive views on physical activity and exercise. Additionally, all participants involved are from a single city and or single cancer centre. A key strength of the scoping study was the comparison of opinions of both patient professionals and people affected by cancer allowing a well-rounded and more in-depth analysis. However, it is possible that other professions could have offered a different perspective. For example, the sample did not include a cancer surgeon since Weston Park Cancer Centre does not include surgical services. A surgeon is involved with newly diagnosed patients and is therefore ideally placed to have key role in promoting the merits of prehabilitation.

Conclusion

This study aimed to gather opinions on exercise for cancer and the critical factors to design an exercise referral pathway. PABC and professionals both acknowledge the benefits of being physically active before and after treatment. PABC express uncertainty in how much exercise they should be doing and how to recognise when they are doing too much. Patients also identified that they received very little support or

encouragement to be active from health professionals. Thus, there is a gulf between the patients' needs and the health professionals' priorities. Addressing the knowledge gaps, and fears around exercise will be critical to providing impetus to behaviour change. This study provides evidence to inform the development of an exercise referral pathway and key success indicators for people affected by cancer.

Future directions

Following this study, we used the findings from PABC and the professional stakeholders to develop and implement a pilot exercise service for PABC in Sheffield. Additionally, the team subsequently piloted professional development sessions on exercise for PABC for health professionals to increase their knowledge and confidence in introducing conversations about exercise with PABC. Finally, a recommendation for further study is to understand why health professionals may not routinely and consistently initiate discussions regarding exercise with PABC.

Acknowledgements

The authors would like to express gratitude to all the participants involved in the study. We also wish to thank Emeritus Professor of Health Services Research at Sheffield Hallam University, Prof Karen Collins on her contributions to the early design of the study. Diana Greenfield is a National Institute for Health Research (NIHR) Senior Nurse Research Leader. The views expressed in this article are those of the author and not necessarily those of the NIHR, or the Department of Health and Social Care. This study was funded by a research award from Weston Park Cancer Charity, Sheffield.

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Table 1: Interview schedules

Topic area	Sample questions
Interview schedule for PABC	
Exercise for cancer Participants to discuss their understanding of exercise, and the barriers and facilitators to participation	What are your views regarding exercise for PABC? What support do PABC need to engage in exercise? How do you think we should approach helping people with cancer be more active?
Accessibility of exercise for PABC	What might stop you from performing regular exercise (barriers)? How might you overcome these barriers? Have you been given advice in the past from health professionals regarding exercise?
Cancer exercise services Participants to discuss their thoughts on the critical factors to implement an exercise service for PABC	What do you think are the most important components of an exercise service for PABC?
Interview schedule for professional stakeholders	

Exercise for cancer Participants to discuss their knowledge of exercise, and the barriers and facilitators to participation	What are your views regarding exercise for cancer patients? Are you aware of the current physical activity recommendations for someone who has been diagnosed with cancer?
Accessibility of exercise for PABC Participants discussed screening of participants, discussions of exercise	Do you feel there are any gaps in current service provision with regard to physical activity and exercise and cancer patients? How are these best addressed? Does your current role require you to discuss exercise to cancer patients and survivors? At what stage should exercise be recommended to patients? (from diagnosis, pre-post treatment, living with and beyond cancer)
Cancer exercise services Participants to discuss the critical factors to implement an exercise service for PABC	What do you think are the most important components of an exercise service for PABC? What do you feel would be the key performance indicators for such a service?

Table 2: PABC main themes and sub-themes

Main theme	Sub-themes
Theme 1: Thoughts on exercise following a cancer diagnosis	1. Health benefits of exercise 2. Loss of personal control following a diagnosis 3. Enhancing recovery from cancer
Theme 2: Barriers to participating in exercise	1. Fear of making their health worse 2. Low confidence in their ability to exercise

	3. Cancer-related fatigue
Theme 3: Lack of advice on how and when to exercise	<ol style="list-style-type: none"> 1. No support from clinical teams 2. Lack of encouragement from health professionals 3. Timing of discussions about exercise is important
Theme 4: Critical factors for an exercise service	<ol style="list-style-type: none"> 1. Social/peer support 2. The financial implications of a cancer diagnosis must be considered 3. Exercise must be tailored to the individual 4. PABC need to be taught how to pace their exercise. 5. Exercise professionals must be appropriately trained

Table 3: Professionals main themes and sub-themes

Main themes	Sub-themes
Theme 1: Opinions on exercise for PABC	<ol style="list-style-type: none"> 1. Endorsement of exercise 2. The need for tailored exercise 3. Communicating the exercise message
Theme 2: Barriers to implementing an exercise referral service for PABC	<ol style="list-style-type: none"> 1. The financial implications of exercise options 2. Challenges to promoting exercise to PABC 3. Professionals will not refer PABC to services due to a lack of trust
Theme 3: Critical Factors to ensure a service is effective	<ol style="list-style-type: none"> 1. Exercise options must be easily accessible for PABC 2. An exercise service must be effective and sustainable 3. Exercise professionals need to be appropriately trained